A Resource Guide for Families Dealing With Mental illness

The Alliance for the Mentally ill of Michigan
The Michigan Department of Community Health

The NAMI–Michigan Family Resource Guide

If someone in your family has a mental illness, you are not alone. Members of NAMI Michigan have learned the hard way about mental illness and services available. We have compiled information in this manual that would have been useful to us at the beginning, in the hope that it will be helpful to others as they find ways to understand and cope with mental illness in their family.

Mental Illness: A Family Resource Guide was written for and dedicated to families who have a relative with mental illness. The first edition, published in 1988, came about through the initiative of Yolanda Alvarado and other members of NAMI Michigan who saw the need to share what they knew with other families. It was written and revised by Carol Rees, NAMI of Washtenaw County.

Many family members, consumers, and mental health professionals reviewed the text and contributed to subsequent revisions. Special thanks is due to Bradley Geller, Counsel, Washtenaw County Probate Court, and to Marjorie Hartnett, NAMI of Grand Traverse and Leelanau Counties, for the sections on voluntary and involuntary treatment.

Cover graphic design by Donna Murdoch, NAMI Wisconsin. The iris is the NAMI national flower, chosen because Vincent Van Gogh painted many irises while hospitalized at Saint Remy for mental illness.

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I. INTRODUCTION

Purpose of this manual

If someone in your family has a mental illness, you are not alone. Members of NAMI Michigan have learned the hard way about mental illness and services available. We have compiled information in this manual that would have been useful to us at the beginning, in the hope that it will be helpful to others as they find ways to understand and cope with mental illness in their family.

NAMI Michigan

NAMI Michigan is part of a national organization "dedicated to the eradication of mental illness and to the improvement of the quality of life of those whose lives are affected by these diseases." There are more than a thousand NAMI affiliates in this country, forty of them in Michigan. Members include families and friends of individuals with mental illness, and those who suffer from mental illness. There are also groups in a number of other countries. The national organization is at Colonial Place Three, 2107 Wilson Blvd., Suite 300, Arlington, VA 22201, phone 703/524-7600.

Purposes of NAMI Michigan are:

- Encouraging and assisting in the organization of local affiliate groups within the state of Michigan composed of families and friends of persons with mental illness.
- Serving as an information and collection and dissemination center.
- Monitoring existing health care facilities, staff, and programming for adequacy and accountability.
- Promotion of new and remedial legislation.
- Fostering public education.
- Pressing for quality institutional and non-institutional treatment of persons with mental illness.
- Promotion of community support programs, including appropriate living arrangements linked with supportive social, vocational rehabilitation, and employment programs.
- Providing for family support.
- Supporting and advocating for research into the causes, alleviation, and eradication of mental illness.
- Improvement of private and governmental funding for mental health facilities

and services, care, and treatment; and for residential and research programs.
- Liaison with other mental health organizations.
- Delineation and enforcement of patient and family rights.

Most people who join a NAMI affiliate do so because they need information and ways to cope with mental illness of a family member or themselves. They learn by talking with others, by attending educational meetings, and through affiliate newsletters. We encourage you to call the group nearest you and attend their meetings. You can locate local affiliates on the NAMI Michigan website, www.mi.nami.org, or call the state office at 517/485-4049 or 800/331-4264.

II. MAJOR MENTAL ILLNESS

Symptoms of mental illness

Mental illness refers to a group disorders that cause severe disturbances in thinking, feeling, and relating, often resulting in an inability to cope with the ordinary demands of life. They cause great distress to the person affected. Symptoms vary, and every individual is unique. But all persons with mental illness have some of the thought, feeling, or behavioral characteristics listed below. The list was developed by a group of family members from NAMI Arizona. While a single symptom or isolated event is not necessarily a sign of mental illness, professional help should be sought if symptoms increase or persist.

- **Social withdrawal:** Sitting and doing nothing; friendlessness; abnormal self-centeredness; dropping out of activities; decline in academic or athletic performance.
- **Depression:** coming out of nowhere, unrelated to events or circumstances; loss of interest in once pleasurable activities; expressions of hopelessness; excessive fatigue and sleepiness; inability to sleep; pessimism; perceiving the world as "dead"; thinking or talking about suicide.
- **Thought disorders:** Inability to concentrate or cope with minor problems; irrational statements; peculiar use of words or language structure; excessive fears or suspiciousness.
- **Expression of feelings:** hostility from one formerly passive and compliant; indifference, even in highly important situations; inability to cry; excessive crying; inability to express joy; inappropriate laughter.

- **Behavior:** hyperactivity or inactivity, or alternating between the two; deterioration in personal hygiene. Noticeable and rapid weight loss; drug or alcohol abuse; forgetfulness and loss of valuable possessions; attempts to escape through geographic change; frequent moves or hitchhiking trips; bizarre behavior (staring, strange posturing); unusual sensitivity to noise, light, clothing.

Often the symptoms of mental illness are cyclic, varying in severity from time to time. The duration of an episode also varies; some persons are affected for a few weeks or months while for others the illness may last many years or a lifetime.

Accurate diagnosis may take time. The initial diagnosis is often modified later, perhaps several times. It takes time to evaluate response to treatment, a very important piece of information. It may also be difficult to pinpoint the problem because the individual has more than one disorder; for example, schizophrenia with an affective disorder, or an anxiety disorder such as obsessive compulsive disorder with depression or a personality disorder. It is important for the psychiatrist to reevaluate the diagnosis from time to time in order to work out the best treatment approach.

In many cases of apparent mental illness, alcohol or drug abuse or an underlying medical disease such as hypothyroidism or a brain tumor is found to be the problem. A thorough physical examination should be the first step when mental illness is suspected.

Kinds of mental illnesses

Schizophrenia

The word schizophrenia comes from Greek terms meaning "splitting of the mind." People with schizophrenia, however, do not have a split personality. They have a disorder that affects thinking and judgment, sensory perception, and their ability to interpret and respond to situations appropriately. There usually are drastic changes in behavior and personality. Lack of insight about the illness is one of the most difficult symptoms to treat, and may persist even when other symptoms (e.g., hallucinations and delusions) respond to treatment.

Schizophrenia will affect about 1% of the population at some time during their lifetime. It is usually first diagnosed between the ages of 17 and 25. There may be several psychotic episodes before a definite diagnosis is reached.

When the disease first appears, the person feels tense, and has difficulty concentrating. He/she begins to withdraw; school work or work performance may deteriorate; general appearance may deteriorate; and friends may drift away. Parents often think that this is just adolescent behavior gone astray, and even doctors may be uncertain about a diagnosis in the early stages.

Signs and symptoms of schizophrenia include:

- **Alteration of the senses.** The senses (sight, hearing, touch and/or smell) may be intensified, especially early in the disease.
- **Inability to process information and respond appropriately** (also known as "thought disorder"). Because the individual has difficulty processing external sights and sounds, and because he/she experiences internal stimuli that others are not aware of, the response is often illogical or inappropriate. Thought patterns are characterized by faulty logic, disorganized or incoherent speech, blocking, and sometimes neologisms (made-up words). He/she may relate experiences and concepts in a way that seems illogical to others, but that holds great meaning and significance for that person.
- **Delusions.** These are basically false ideas which the person believes to be true, but which cannot be, and to which the individual adheres in the face of reason. However, unusual beliefs may be the product of a person's culture, and can only be evaluated in this context. Two common kinds of delusions are paranoid delusions, characterized by belief that one is being watched, controlled, or persecuted; and grandiose delusions, centered on the belief that one owns wealth or has special power, or is a famous person, often political or religious.
- **Hallucinations.** Hallucinations are sensory perceptions with no external stimuli. The most common hallucinations are auditory; hearing "voices" which the person may be unable to distinguish from the voices of real people.
  Delusions and hallucinations are the result of overacuteness of the senses and an inability to synthesize and respond appropriately to stimuli. To the person experiencing them, they are real. Medications can be very helpful in controlling illogical thinking and hallucinations.
- **Changes in emotions.** Early in the illness, the person may feel widely varying, rapidly fluctuating emotions and exaggerated feelings, particularly guilt and fear. Emotions are often inappropriate to the situation. Later there may be apathy, lack of drive, and loss of interest and ability to enjoy activities.
- **Changes in behavior.** Slowness of movement, inactivity, withdrawing are common. Motor abnormalities such as grimacing, posturing, odd mannerisms, or ritualistic behavior are sometimes present. There may also be pacing, rocking, or apathetic immobility.

There is yet no cure for schizophrenia, but there are many medications available which can reduce the symptoms. Finding the right medication(s) is a very complex process and demands a working relationship with a doctor that is based on trust. The outcome can be very successful when the individual is treated appropriately with medications and also has access to rehabilitation services and a stable, supportive living environment.

Mood disorders

Mood disorders or affective disorders include depression and bipolar disorder (manic depression). They are the most common psychiatric problems. The terms mood and affect refer to the state of one's emotions. A mood disorder is marked by periods of extreme sadness (depression) or excitement (mania) or both (bipolar disorder). If untreated, these episodes tend to recur or persist throughout life. Even when treated, there may be repeated episodes.

Beyond persistent depressed mood, the symptoms of depression include:

- Loss of interest in daily activities; loss of energy and excessive tiredness
- Poor appetite and weight loss, or the opposite: increased appetite and weight gain
- Sleep disturbance: sleeping too little or sleeping too much in an irregular pattern
- Feelings of worthlessness, or guilt that may reach unreasonable (delusional) proportions
- Recurrent thoughts of death or self-harm; wishing to be dead or attempting suicide
- Poor concentration

Symptoms of hypomania, or the more severe state of mania, include:

- Euphoric, expansive mood; or irritable mood
- Boundless energy, enthusiasm, and activity
- Decreased need for sleep
- Rapid, loud, disorganized speech
- Short temper, argumentativeness
- Delusional thinking
- Activities which have painful consequences, i.e. spending sprees or reckless driving

Estimates of the number of people with bipolar disorder vary from about 0.8% to 1.5% of the population. The illness often first appears in childhood or adolescence, although the majority of cases begin in young adulthood. There is believed to be a genetic component to the illness, since depression and bipolar illness often run in families.

Ironically, some of the symptoms of mania lead affected people to believe that they are not sick in fact, they may never have felt better. The euphoric mood may continue

even in the face of sad or tragic situations. Even when the person continues to feel swept up in a mood of excitement, family and friends may notice serious problems. For example, people with mania often go on spending sprees, become promiscuous, or abuse drugs and alcohol while being unaware of the serious consequences of their behavior. Fortunately, bipolar disorder is one of the most treatable illnesses. Lithium (see section on medications) is effective for 70% of people with bipolar disorder. There are a number of other medications for those who do not respond to lithium or who for some reason cannot take the medication. In addition to medication, many people with bipolar disorder find individual psychotherapy and/or peer support groups helpful. Since many of the symptoms of mania may also occur in schizophrenia, it is often difficult to diagnose which of these illnesses an individual has.

Depression in some degree will affect between 10% and 20% of the population at some time during their lives. Severe, recurrent depression will affect between 3% and 5%, some as often as once or twice a year, with episodes which may last longer than six months each. People with the most severe depression find they cannot work or participate in daily activities, and often feel that death would be preferable to a life of such pain. Depression is thought to be the cause of as many as 75% of suicides.

Probably more than with any other illness, people with depression are blamed for their problems and told to "snap out of it," "pull themselves together," etc. Often others will say a person "has no right" to be depressed. It is critical for family and friends to understand that depression is a serious illness; the person with this illness can no more snap out of it than a person with diabetes can will away that illness. Depression is a very treatable illness. Approximately 70% to 75% of people properly diagnosed respond to treatment. There are many types of depression, and each responds somewhat differently to antidepressant medications and psychotherapy.

Schizoaffective disorder

This illness is a combination of psychotic symptoms such as hallucinations or delusions, and significant mood symptoms, either depression or mania, or both. The psychotic symptoms persist when the mood symptoms resolve.

Other disorders

Anxiety disorders include the phobias, panic disorder, obsessive-compulsive disorder (OCD), and posttraumatic stress disorder. Symptoms may be so severe as to be disabling, but these illnesses seldom involve psychosis. Panic attacks come "out of

the blue" when there is no reason to be afraid. Symptoms include sweating, shortness of breath, heart palpitations, choking, faintness. With OCD, the individual may have only obsessions or only compulsions, but most have both. Obsessions are repeated, intrusive, unwanted thoughts that cause extreme anxiety. Compulsions are ritual behaviors that a person uses to diminish anxiety. Examples are hand washing, counting, repeated checking, and repeating a word or action.

Personality disorders such as borderline personality and behavior disorders can also be disabling. The individual may receive some benefit from medications and/or psychotherapy.

Dual diagnosis of mental illness and substance disorder the combination of mental illness and substance abuse is very common. Drug and alcohol abuse may seriously complicate mental illness, but are not the primary cause of the illness. People with mental illness often use alcohol or other substances to obtain relief from symptoms and from feelings of despair and loneliness associated with their disease.

Suicide may be a manifestation of mental illness, but not all persons who commit suicide are mentally ill.

Signs of depression, and warning signals of suicide include:

- Change in personality: usually sad, withdrawn, irritable, anxious, tired, indecisive, apathetic or moody
- Change in behavior; difficulty concentrating on school, work or routine tasks; loss of appetite; crying
- Change in sleep patterns: oversleeping or insomnia, sometimes with early waking
- Loss of interest in friends, sex, hobbies or other activities previously enjoyed
- Fear of losing control, "going crazy," or harming oneself or others
- Worries about money or illness, either real or imagined
- Feelings of helplessness and worthlessness
- Sense of hopelessness about the future
- Drug or alcohol abuse
- Recent loss through death, divorce, separation or a broken relationship; also loss of a job, money, status, self-confidence or self-esteem
- Loss of religious faith
- Suicide threats and previous attempts. Alluding to plans about "leaving," either by giving away favorite possessions or revealing a desire to die
- Agitation, hyperactivity and restlessness

Threats of suicide or actual attempts should always be taken seriously. Find out, if you can, whether the person has some specific plan. Ask if he/she has a counselor or physician who might be notified. If you believe the situation may be dangerous, do not hesitate to contact your local 24-hour mental health crisis service, local psychiatric emergency service, or emergency 911 for help.

Serious disorders of children and adolescents

Some psychiatric disorders such as autism typically start in childhood, while others such as mood disorders may be diagnosed in childhood, adolescence, or adulthood. Although there is still much to learn about childhood disorders, it is generally accepted that many, if not most, of the disorders listed below are primarily biological in nature; that is, based on structural and/or chemical abnormalities in the brain.

Autism and other pervasive developmental disorders, schizophrenia, and schizoaffective disorder are clearly biologically based, resulting from a malfunction of the brain. Other disorders, including attention deficit hyperactivity disorder, anxiety disorders, obsessive-compulsive disorder, Tourette's disorder, and mood disorders may also be primarily biologically based, and generally respond to drug therapy. For such disorders, appropriate medical diagnosis and treatment are essential. If a child cannot process information or is not in control of his emotions, psychosocial and educational strategies alone are not likely to be effective.

Professionals have long been reluctant to "label" children with a mental illness diagnosis, given the uncertainties about behavior that may be due to developmental problems, the impact of illegal drugs or alcohol, and the ordinary emotional turmoil that accompanies the passage from adolescent to adulthood. But families need to know what is wrong with their child. There is dignity and hope in a diagnosis. Furthermore, a diagnosis is essential to the task of designing an effective treatment and educational approach.

Some specific disorders described in the Diagnostic and Statistical Manual of Mental Disorders are:

- **Autistic disorder.** The child fails to relate normally to parents and other people, and has play which is rigid, repetitive and lacks variety. Seventy-five per cent of children with autistic disorder also have mental retardation. Once present, autism typically affects the person for life, although about one-third of affected individuals will be able to attain some degree of independence.

- **Attention deficit hyperactivity disorder.** Either inattention or hyperactivity may be present, or both may occur. Inattention: The individual has difficulty paying attention, does not seem to listen when spoken to, and often makes careless mistakes.

- **Hyperactivity:** the individual talks excessively, intrudes on others, has difficulty sitting still or playing quietly. Such behaviors occur both at school and at home.

- **Anxiety disorders.** Anxiety may or may not be associated with a specific situation. Anxiety and worry may be far out of proportion to the actual likelihood or impact of a feared event. Included among the anxiety disorders are panic attacks, social phobia, obsessive compulsive disorder and posttraumatic stress disorder.

- **Mood disorders.** (bipolar disorder; depression). In children, aggressive or hostile behaviors may mask underlying depression. Parents should consider the possibility of depression when there are unexplained somatic complaints, a drop in school performance, social withdrawal, apathy, increased irritability, tearfulness, sleep or appetite changes, and/or suicidal behavior or ideation.

- **Schizophrenia**. Schizophrenia usually starts in the late teens or 20s, and seldom occurs before adolescence, but some cases at age 5 or 6 have been reported. There is evidence, however, that certain structural changes in the brain are present at birth in individuals who later develop schizophrenia. The essential features are the same for children and adults, but it may be difficult to diagnose in children.

- **Tourette's disorder.** Often begins when a child age 5 to 7 begins to have tics such as eye blinking, grimacing, or shoulder jerks. Sudden vocalizations (barks, clicks, yelps) may appear later, and still later the person may involuntarily say words or phrases. Uttering obscene words out of context occurs in less than 10% of patients. Community Mental Health services are also available for children under the age of 18 and their families. Such services include assessment, outpatient counseling

and treatment, crisis intervention and when indicated, hospitalization. Community based support services such as assertive treatment and respite services may also be available. Social Security, SSI and Medicaid may be available for children.

Crisis intervention

If the individual with mental illness is in danger of physical injury, if his or her behavior is out of control or others are in danger, it is important to know what steps to take. Plan ahead by locating available sources for help: your emergency phone number (911), police or sheriff department number, Community Mental Health crisis or emergency number, name and phone number of a mental health professional, friends or neighbors who may be of help, and the nearest NAMI affiliate. Keep these numbers posted by the telephone. Consult ahead of time with the social worker or psychiatrist and with Community Mental Health so you will know how to obtain services when you need them.

If you sense a deterioration in your relative's mental condition, try to find out what is going on. Everyone occasionally has a bad day. However, there are usually early warning signs that signal problems; changes in sleep or social activities; increasing hostility or suspiciousness. Try to get him/her to see a psychiatrist or social worker. The objective is to avert a crisis.

If you should have to call for help in a crisis, take with you written information about the family member's diagnosis, medications, and a description of the specific behavior that precipitated the crisis. It may be useful to have several copies to give to the police and to mental health professionals.

Most of us have had the experience of having our relative who is mentally ill missing for various lengths of time. Often they are later found in a shelter or jail. NAMI has a network of volunteers who may be able to help in locating the missing person. Call NAMI Michigan for the name of our volunteer.

Seeking treatment

The most expensive care is not necessarily the best. Private care is not necessarily better than the care offered through your local Community Mental

Health Services Program. In fact, care through the public sector may be necessary before certain community services are accessible.

When the need for treatment is evident, family members may be at a loss as to what to say or do in order to succeed in getting the help that is needed. Here are some suggestions:

- Most important, understand it is neither your fault nor the fault of the person who is in crisis.
- Be informed as to what resources are available. Contact your local Community Mental Health Services Program and/or NAMI affiliate.
- Evaluate the situation. If you feel there is danger to any person, call the emergency number (911) or law enforcement officer. If a crisis occurs but there appears to be no immediate risk, take your relative to a psychiatric emergency service or call the crisis intervention team.
- If the need for intervention is not urgent, take time to talk with your relative. Stress that you care and are concerned. Do not suggest a diagnosis; just explain that you want them to see someone to determine if they need help. Ask them how they feel and how they feel about talking with a doctor or therapist. Be honest and direct. Use terms that you believe are most acceptable to them (e.g., unhappy, nervous, mixed-up, worried). Respect their right to choose. Understand that they may need to deny what is happening at first, but by discussing it with them you have "opened the door" and they may later be ready to talk and/or seek help.
- Understand their fears. Be patient and supportive. Accept that they may be more willing to talk with a trusted friend, doctor, clergy, or another family member.
- Always be honest. Your relative needs to know he/she can trust you. Discuss commitment with them if this is a possibility. Do not hide books about mental illness. Do not make threats if you do not plan to follow through.
- It will not help to argue or deny that what your relative is seeing, hearing and feeling is real. Instead, assure them that you love them and understand what they are experiencing is real to them, and you want to help them.
- Share your concerns with other family members and try to get their cooperation. Understand they may disagree, deny, or feel stigmatized by the idea of a family member having a mental illness.
- If their condition deteriorates, if you have serious concerns about their well

being and you believe a crisis is imminent, and if they refuse to voluntarily seek treatment, you may need to pursue an involuntary order for treatment.

Voluntary and involuntary hospitalization

Voluntary hospitalization.

It is always preferable for someone to be hospitalized voluntarily, if possible. Anticipating crisis situations and developing a plan ahead of time may facilitate voluntary hospitalization. Even after an application or petition for involuntary hospitalization has been initiated, formal commitment can be avoided if the person agrees to cooperate with the treatment plan proposed at the deferral meeting held soon after admission to the hospital.

Involuntary hospitalization.

If possible, explain your intention to obtain an involuntary order and the reasons for it. Your relative may seek out authorities or other family members to "intervene." This is their right. Be prepared; be calm, firm and consistent. Emphasize that you (or another) is petitioning for them to be examined by a qualified professional to determine the need for treatment.

In order for a person to be involuntarily hospitalized, they must meet the Michigan Mental Health Code definition of a "person requiring treatment." A person may be seriously mentally ill and still not fit that definition. The Probate Court, based on statements made by the person initiating the proceedings and by either two physicians or one physician and one clinical psychologist, makes the determination as to whether the individual is a person requiring treatment. Probate judges vary somewhat in their interpretation of the Code.

The Michigan Mental Health Code defines mental illness as "a substantial disorder of thought or mood that significantly impairs judgment, behavior, capacity to recognize reality, or ability to cope with the ordinary demands of life." Mental illness alone, however, is not sufficient to justify involuntary hospitalization. The Mental Health Code defines "person requiring treatment" as follows:

§330.401 "Person requiring treatment" defined; exception.

Sec. 401. (1) As used in this chapter, "person requiring treatment" means (a), (b), or (c):

(a) An individual who has mental illness, and who as a result of that mental illness can reasonably be expected within the near future to intentionally or unintentionally seriously physically injure himself or another individual, and who has engaged in an act or acts or made significant threats that are substantially supportive of the expectation.
(b) An individual who has mental illness, and who as a result of that mental illness is unable to attend to those of his or her basic physical needs such as food, clothing, or shelter that must be attended to in order for the individual to avoid serious harm in the near future, and who has demonstrated that inability by failing to attend to those basic physical needs.
(c) An individual who has mental illness, whose judgment is so impaired that he or she is unable to understand his need for treatment and whose continued behavior as the result of this mental illness can reasonably be expected, on the basis of competent medical opinion, to result in significant physical harm to himself or herself or others. This individual shall receive involuntary mental health treatment initially only under the provisions of sections 434 through 438 of this act.

(2) An individual whose mental processes have been weakened or impaired by a dementia, an individual with a primary diagnosis of epilepsy, or an individual with alcoholism or other drug dependence is not a person requiring treatment under this chapter unless the individual also meets the criteria specified in subsection (1). An individual described in this subsection may be hospitalized under the informal or formal voluntary hospitalization provisions of this chapter if he or she is considered clinically suitable for hospitalization by the hospital director.

Any person 18 years or older may file a petition/application which asserts that an individual is a person requiring treatment. This may be a family member, friend, mental health worker, police officer, or any adult who has direct knowledge on which to base their assertion that the person requires treatment. Since procedures vary from county to county, check with your local Community Mental Health Services agency for information and assistance.

There are two ways to initiate commitment procedures:
by **clinical certification** through the local Community Mental Health Services Program, or by **petition** directly to the Probate Court:

Admission by clinical certification. A relative, mental health worker, police officer or other person may take a person who appears to be mentally ill to a physician, hospital or pre-admission screening unit of the local Community Mental Health Services Program for assessment. **An Application for Hospitalization** form must be completed.

The form requires examples of recent behaviors which have been directly observed by the person filling out the form, and why the individual needs to be hospitalized. (See Section 401 criteria on previous page.) The form must also include the names and addresses of witnesses and the name and address of the person's nearest relative, guardian or friend. The form may be obtained through Probate Court or your local Community Mental Health Services Program. (See Appendix B.)

A physician or clinical psychologist will examine the individual. If the doctor finds that the individual meets the criteria for admission, he/she will fill out a Clinical Certificate stating that the person examined requires treatment. The individual will then be admitted to a hospital and a second assessment and Clinical Certificate will be completed by a psychiatrist.

If the mental health professional who conducts the preadmission screening denies hospitalization, the relative or other involved person may request a second opinion and an additional evaluation will be performed as soon as possible.

Within 72 hours of admission, excluding Sundays and holidays, the individual will have a deferral meeting in the hospital and be assigned representation by a lawyer. The patient may also designate a friend or relative to attend. At this meeting, a representative from the Community Mental Health Services Program and one from the hospital will present a proposed treatment plan. If the person agrees to cooperate with this plan, he/she is accepted as a voluntary patient. However, if at any time during the course of treatment the person refuses to accept the agreed-on treatment, the hospital may notify the Probate Court and a court hearing will be held on the original application.

The hearing will be held within 7 days of the date that all necessary forms are received by the Probate Court. It will be necessary for the individual who signed the application to be in court in order to testify about the person's behavior.

Admission by petition. A **Petition** for hospitalization requires the same form **(Petition/Application** form) and information as for admission by Clinical Certification described above. The main difference between the two procedures is that the **Petition** is filed directly with the Probate Court. A **Clinical Certificate** should accompany the petition, but if it is not possible to obtain one, the Probate Court can order (by police transport if necessary) the person to be examined by a psychiatrist and either another physician or a clinical

psychologist. If the person is found to be a person requiring treatment, there will be a deferral meeting. Then, a court hearing will be held within 7 days after the Probate Court receives the necessary forms, if the person does not agree to defer the hearing and accept the treatment plan as outlined in the individual's plan of service.

Admission by petition is of course limited to the availability of a judge, which in most communities means weekdays between 8:00 a.m. and 5:00 p.m.

Since the interpretation of "potentially dangerous to self or others," and "unable to care for basic physical needs such as food, clothing or shelter" varies, it may be difficult to obtain admission to the hospital even in an obvious emergency. Families may need to be assertive. Respect the fact that, as family, you know your relative better than anyone and are your relative's strongest advocate. Do not hesitate to continue to pursue what you believe to be in his/her best interest. It may help to have someone along who has experience with commitment procedures; call your local NAMI affiliate for assistance. A police officer who has responded to a crisis can be helpful by assisting in getting the individual to the hospital and being a witness at the court hearing.

If you fill out the application, and later when you testify at the hearing, it is important to be specific and give concrete examples of ways the behavior is dangerous to the mentally ill person or others. Avoid "second hand" information. Don't diagnose (e.g., "he acts paranoid; hallucinates; appears depressed)." In your statement, try to demonstrate the risk at the present time. Some examples of how to describe the situation are: "She sits in a darkened room all day and won't eat anything except coffee. She leaves notes around the house saying she doesn't want to go on living. Here is such a note." Or, "He threw a jar of mayonnaise at me, and if I had not ducked I could have been seriously hurt. He has done similar things to other family members." "He threw a chair at his sister." "He drives his car recklessly, endangering people, backing out of the driveway without looking, hitting fences and curbs."

Initiating procedures for involuntary treatment can be extremely difficult for families, who love their relative and respect his/her right to self-determination. A family member's role in making application is, in effect, simply describing the behavior which they believe indicates the need for and right to treatment. The Mental Health Code exists to protect an individual's rights. The Probate Court, taking into consideration the information provided by mental health professionals, ultimately makes the decision as to whether the person requires treatment.

Alternative treatment orders (ATO)

If the court orders alternative treatment, this means outpatient treatment, generally through Community Mental Health. It will be ordered at the commitment hearing, and is usually in addition to a period of hospitalization. The criteria are the same as for involuntary hospitalization; that is, the person must be found by the Probate Court to be a "person requiring treatment."

An individual under court order for alternative treatment is required, after discharge from the hospital, to keep appointments with the clinic or physician and to cooperate with the prescribed treatment. Medications are often given by injection at intervals of a week to a month, in order to assure medication compliance. The individual may be returned to the hospital by order of the court if he/she does not comply, or if the order is not sufficient to prevent harm or injuries. This does not require another court hearing.

Alternative treatment orders are designed to ensure treatment for a person who can be expected to deteriorate if not treated, but who no longer needs to be hospitalized. The initial order is for up to 90 days of combined inpatient and outpatient treatment, and may be extended for up to one year. Extension of the alternative treatment order can be accomplished during the final 14 days of the period of the order, without a court hearing, if the director of the treatment program requests it and the Probate Court agrees.

Michigan Mental Health Code, §330.469, alternative treatment orders:
(3) If the court finds that a treatment program which is an alternative to hospitalization is adequate to meet the individual's treatment needs and is sufficient to prevent harm or injuries which the individual may inflict upon himself or herself or upon others, the court shall order the individual to receive that treatment for a period of not more than 90 days.

(4) If the court finds that a treatment program which is an alternative to hospitalization would be adequate to meet the individual's treatment needs following an initial period of hospitalization, and that the program is sufficient to prevent harm or injuries which the individual may inflict upon himself or herself or upon others, the court shall order the individual to received combined hospitalization and alternative treatment for a period of not more than 90 days. The hospitalization portion of the order shall not exceed 60 days.

(10) Before the expiration of a 90-day order of alternative treatment or of combined hospitalization and alternative treatment, if the director of the hospital or the agency or mental health professional directed to supervise the individual's alternative treatment program believes that the individual continues to require treatment, and if the individual is expected to refuse to continue treatment on a voluntary basis when the order expires, then the hospital, agency, or mental health professional may petition the court for a determination that the individual continues to be a person requiring treatment and for an order authorizing 1 of the following:

(a) Hospitalization for a period of not more than 90 days from the date of issuance of the second order.
(b) Combined hospitalization and alternative treatment for a period of not more than 1 year from the date of issuance of the second order. The hospitalization portion of the order shall not exceed 90 days.
(c) Alternative treatment for a period of not more than one year from the date of issuance of the second order.

Guardianship

Guardianship is designation by the Probate Court of a person to make personal decisions on behalf of another person who is judged to be unable to make informed decisions about his/her care. The guardian makes decisions regarding personal care, but is not financially responsible for the person's care. A parent or other family member may want to seek guardianship for a relative who is mentally ill for one of the following reasons:

- The guardian can help the person with mental illness by seeing that he/she is living in a safe place or receives needed medical attention. The guardian may authorize a voluntary admission if the relative agrees. A guardian cannot, however, authorize involuntary hospitalization.
- The guardian has full access to medical records; information which may otherwise be impossible to obtain.

Medications

Psychotropic medications are often very useful in helping the person with mental illness to think more clearly, to gain control of his/her own thoughts, actions,

and emotions. They can also dramatically decrease the need for hospitalization and increase the ability to benefit from rehabilitation programs and function independently. Any licensed physician, not just a psychiatrist, may prescribe medications. A psychiatrist, however, is more knowledgeable about these medications and should supervise ongoing drug treatment.

It is important for you and your relative to know the names of prescribed medications, their dosage, therapeutic benefits, any side effects observed, and any risks or precautions. Your relative should also have all of this information. Since some persons have reported differences in response to drugs from different manufacturers, you should note both the trade name (generally capitalized) and generic name (generally lower case) for each medication prescribed. Keep a written record of this information, with dates, for each drug prescribed. Be sure other doctors (and dentists) know what medications your family member is taking.

Medications produce both beneficial effects and side effects. People are highly variable in regard to how much benefit they will get from a drug and the type and severity of the side effects they will experience. While side effects usually are evident soon after starting to take the medication, the desired effect may not be seen for several weeks, and may take months of continuous use before the maximum benefit is evident. Some side effects, especially those that appear early, are temporary and may go away or become less severe after a few weeks. Most side effects are related to drug dose; the higher the dose, the worse the side effect.

Resistance to taking prescribed medications is often due to unpleasant side effects. It is important that the prescribing physician discuss this with the patient and seek the most effective and acceptable plan for treatment. Your family member will be given an explanation and written summary of the most common side effects of medications which have been prescribed.

There are four main groups of drugs used to treat the symptoms of mental illness:antipsychotics, mood stabilizers, antidepressants, and antianxiety drugs.

Antipsychotics

These medications are for treatment of the symptoms of psychosis, which include unusual or bizarre behavior, hallucinations, delusions, agitation, and disturbed thought processes. They are also sometimes used to calm the severely

hyperactive behavior seen in the manic phase of bipolar disorder. They can help prevent relapse and/or hospitalization.

Some of the more commonly used antipsychotic drugs:

Clozaril (clozapine)
Risperdal (risperidone)
Geodon (ziprasidone)
Seroquel (quetiapine)
Haldol (haloperidol)
Stelazine (trifluoperazine)
Loxitane (loxipine)
Thorazine (chlorpromazine)
Mellaril (thioridazine)
Trilafon (perphenazine)
Navane (thiothixene)
Zyprexa (olanzapine)
Prolixin (fluphenazine)

Clozaril (clozapine) affects the bone marrow, and therefore blood monitoring is required. Haldol (haloperidol) and Prolixin (fluphenazine) come in long-acting forms and can be administered by injection at intervals of one, two or several weeks. This can be useful for individuals who tend to be forgetful or noncompliant. Risperdal (risperidone) also comes in liquid form, and Zyprexa (olanzapine) comes in a wafer that dissolves in the mouth.

Some significant side effects of this group of drugs are:

- Allergic reactions. If these occur, it is usually in the first two months of treatment. If any of the following occur during this time, notify the physician: rash, fever, sore throat, stomach pain, vomiting, diarrhea.
- Autonomic reactions. These side effects include dizziness or fainting when first sitting or standing, dry mouth, blurred vision, difficulty in urinating, constipation. They may decrease or disappear with time.
- Drowsiness. This can be troublesome at first, but tends to decrease or disappear after a few weeks.
- Extrapyramidal reactions (movement problems). These include akathisia (restlessness, pacing, rocking, foot tapping), dystonia (muscle spasms; usually in the first few days of treatment), and pseudoparkinsonism (muscle stiffness, tremor, shuffling gait, slow movement, or drooling). They may be treated by reducing the dose of antipsychotic drugs, or by adding drugs such as **Artane**

(trihexyphenidyl) or **Cogentin** (benztropine).

- Tardive dyskinesia. This syndrome sometimes occurs after long term use of antipsychotic drugs. It includes involuntary movements such as tongue protrusion, lip smacking, chewing movements, grimacing or frowning. It may also involve the extremities (finger twitching, arm movements) or other muscle groups in the body. Early signs should be reported to the physician because, unless the drug is changed or the dose reduced, the symptoms may get worse and/or become irreversible.

Mood stabilizers

Lithium is used to reduce the wide swings of mood in persons with bipolar or manic-depressive illness. Blood levels should be checked at intervals to regulate the dose so it will control symptoms with the fewest side effects. Some **side effects** may be nausea, vomiting, diarrhea, abdominal cramps, muscle weakness or tremor, thirst, frequent urination, tiredness or sleepiness, weight gain. If muscle spasms, dizziness, or convulsions occur, stop taking the medication and call the physician. **Depakote** (valproic acid), **Lamictal** (lamotrigine), **Neurontin** (gabapentin), and **Tegretol** (carbamazepine), are also used as mood stabilizers.

Antidepressants

This group of medications is used to treat severe depression and to manage agitated or hostile behavior related to depression. For some persons with bipolar disorder (manic-depression), use of antidepressants may induce hypomania or mania, and over time the frequency of cycles may be increased. Below is a list of some of the more common antidepressants; all require careful monitoring:

Tricyclic antidepressants:
Anafranil (clomipramine)
Elavil (amitryptyline)
Norpramine (desipramine)
Pamelor (nortriptyline)
Sinequan (doxepin)
Tricyclic antidepressants continued:
Tofranil (imipramine)

Atypical antidepressants:
Desyrel (trazodone)

Selective serotonin reuptake inhibitors (SSRIs):
Celexa (citalopram)
Luvox (fluvoxamine)
Paxil (paroxetine); also used for panic disorder
Prozac (fluoxetine)
Zoloft (sertraline)

Mixed serotonin reuptake inhibitors:
Effexor (venlafaxine)

Remeron (mirtazapine)
Welbutrin (bupropion)
Serzone (nefazodone)

Monoamine oxidase inhibitors (MAOIs):
Marplan (isocarboxazid)
Nardil (phenelzine)
Parnate (tranylcypromine)

Side effects of tricyclic antidepressants can include autonomic reactions, stomach upset, weight gain, drowsiness, nightmares, inability to sleep, sexual dysfunction, or increased seizure activity for people with a seizure disorder. Side effects of monoamine oxidase inhibitors may include ringing in the ears, sexual dysfunction, or weight gain. Some serious reactions such as hypertensive crisis, rapid heart rate, and chest pain may result when MAOIs are given with certain foods and drugs. Anafranil (clomipramine), Luvox (fluvoxamine), Prozac (fluoxetine) and some of the other antidepressants are used in the treatment of obsessive compulsive disorder.

Antianxiety agents

This group of medications is used to reduce anxiety, relax muscles and produce sedation. They should generally be used only for short periods of time. Some are addictive and may produce severe reactions if used with alcohol.

Ativan (lorazepam)
Librium (chlordiazepoxide)
BuSpar (buspirone; little risk of addiction)
Serax (oxazepam)
Halcion (triazolam)
Valium (diazepam)
Klonopin (clonazepam)
Xanax (triazolam)

Side effects can include dizziness, drowsiness, loss of muscle coordination, blurred vision, agitation, weight gain, diarrhea.

Resources for care

Mental health professionals

Any of the following may be involved in assessment and planning for treatment and care. Each has specific tasks but is also a part of the treatment team. The duties and responsibilities will vary in different agencies.

- **Psychiatrists** are physicians (M.D. or D.O.) with specific training in psychiatry. They assess, make the diagnosis, and prescribe medications and possibly other treatment. They work with the treatment team to plan for care in the hospital and after discharge. They may provide psychotherapy, either individually or with groups.
- **Psychologists** who possess a Ph.D. are trained and licensed to diagnose and provide treatment services. Masters' level psychologists often administer psychological tests or perform other duties similar to those described for psychiatric nurses and social workers.
- **Psychiatric nurses** have specific training in psychiatry. They generally have major responsibility for direct care in the hospital, day treatment program, or Community Mental Health clinic. They may also do individual or group counseling.
- **Social workers** work with the individual, family and community in the context of the person's total life situation. He/she may offer individual or group counseling. The social worker ordinarily serves as liaison between the treating agency and the family.
- **Case managers** or client services managers coordinate care and services in the community. They assist their clients to receive needed treatment and services from a variety of community agencies. They assist in obtaining access to housing, rehabilitation services, and income programs such as SSI and SSDI. They generally work for Community Mental Health or an agency under contract to Community Mental Health. The term case manager is sometimes used interchangeably with social worker, although education, experience and responsibilities are somewhat different.

Confidentiality

Whether the setting is in a hospital or the community, ask to have your relative sign a Release of Information form so you can be informed about such matters as medications and what treatment and services will be needed after discharge. Mental health professionals may give confidentiality as a reason for not talking to families and may neglect to ask your relative for permission to discuss such matters. However, families cannot meet their responsibility of providing a support system and an environment that is conducive to recovery if they do not receive information and guidance they need.

Your relative may initially refuse permission to share information because he/she is anxious about his situation and has not yet developed a trusting relationship with the therapist. Discuss this with the therapist. Determine if he/she is

supportive of your involvement, and if not, why not. Ask him/her to continue to encourage your relative to allow your participation. Perhaps the problem is limited time, or uncertainty regarding your relative's needs.

Remember, confidentiality belongs to the patient, not the professional. Your relative may fear that matters such as use of drugs and alcohol will be discussed. If the professional makes it clear that only specific kinds of information such as medications or discharge plans will be discussed, gaining the necessary consent will not ordinarily be a problem. Another option is to arrange a meeting with both patient and family members present. Even if consent to release information is not obtained, the mental health professional can listen to family members' concerns and offer information about mental illness such as that usually discussed in family education classes. If confidentiality continues to be a problem, call the agency director or your local NAMI affiliate for assistance.

Community Mental Health Services Programs (CMHSPs)

Because serious mental illness is likely to require treatment over a long period of time, or for an entire lifetime, most persons sooner or later use the services of their local Community Mental Health Services Programs. CMHSPs may be involved in the initial assessment, and will certainly be involved if treatment is involuntary. The entry point for services may be by appointment with an intake worker (social worker and/or psychiatrist), through crisis or psychiatric emergency services, through the commitment process, or by referral from a jail or homeless shelter.

Once a person is determined to be eligible for services, a case manager (client services manager) is ordinarily assigned to assist with such services as crisis intervention, medical diagnosis and treatment, income support, rehabilitation services, and sometimes counseling (therapy) and outreach services. CMHSPs may also offer residential and vocational services to eligible individuals. There may in addition be a family education program to provide support and information to family members.

Payment for Community Mental Health services is based on ability to pay. Parents are not ordinarily financially responsible for their children after they have reached the age of 18.

Hospitals

Hospitals may be sought for emergencies, for voluntary hospitalization, or for involuntary hospitalization (commitment). If the choice is private care rather than through Community Mental Health, there are several things to consider:

- The family can expect to have difficulty finding a private psychiatric hospital willing to accept involuntary admission. Most private psychiatric hospitals and licensed psychiatric units in general hospitals readily accept voluntary patients but are reluctant to admit individuals under a court order. All of the Community Mental Health Services Programs, however, have contractual arrangements in place with both state hospitals and some local general hospitals to provide both voluntary and involuntary inpatient treatment services.
- Private insurance may cover a short hospitalization. Check carefully to see how much of the cost is covered; most policies have very limited coverage for psychiatric problems. Check with your insurance company about continuing your son's or daughter's coverage after the age when coverage generally stops (usually 24). It may be possible to continue coverage past that age on a parent's policy.
- Medicaid may cover hospitalization. The Community Mental Health case manager can assist with applying for Medicaid.
- Community Mental Health may have crisis residential services which provide an alternative to hospitalization in an acute episode, thus avoiding commitment and hospitalization.

Individuals being discharged from a hospital admission arranged by a community mental health services program will ordinarily have priority for services such as Assertive Community Treatment, specialized residential services and other support services. If medical or inpatient psychiatric hospital care has been privately arranged, these services may not be so readily available when it is time for the person to be discharged.

Families that maintain contact and responsibility for their relative who is mentally ill are a vital part of the treatment team. They need to learn what is necessary to carry out their responsibilities, just as other caregivers do. As soon as possible after admission to the hospital, make an appointment with the treatment team to discuss the following:

- What is the diagnosis? Please explain.
- What is the treatment plan?

- What are the specific symptoms about which you are most concerned? What do they indicate? How are you monitoring them?
- What medications have been prescribed? Is the response what was hoped for? What side effects should be watched for?
- Has the doctor or nurse discussed with the patient the diagnosis, the medications, the treatment plan?
- Has he/she been instructed individually or in class about the illness, identification and management of symptoms, and medications prescribed? To what extent does he/she understand what has been taught?
- How often can we meet to discuss progress? What steps will you take to ensure the treatment plan will be continued after discharge, and that appropriate housing and services are available? What should we do if an emergency occurs after discharge?

Ongoing treatment

Serious mental illness is usually a long-term condition; families should plan ahead even if they are fortunate enough to have to deal with only one or two episodes. Families who have lived with mental illness for a long time often describe how carried away they were at the time of the first episode and how they sometimes imprudently committed themselves to expensive treatments in expectation of a cure that was never to be realized.

What most individuals do need is medical diagnosis and treatment, a safe, stable place to live, and a chance to develop or relearn social and vocational skills. The best place to look for services over a long period of time is through your local Community Mental Health Services Program. If such services do not seem to be available, you may need to speak up, contact your county and state elected representatives, or even seek legal advice. Also contact your local NAMI affiliate; they may be able to help you.

The ability of the person with mental illness to learn about his/her illness and to take responsibility for identifying and managing his/her symptoms is important in progressing toward recovery. An understanding of the mental illness, symptoms and treatment; social skills; and problem solving should be a part of both inpatient and outpatient care. Psychosocial clubhouses can also play an important role through peer education and support.

Complaints and grievances

Either the patient or a family member may take the following steps when there are specific complaints or grievances:

- Discuss the problem with the treatment team leader. If this does not resolve the problem, contact that person's supervisor or the director of the agency, hospital, or Community Mental Health Services Program.
- For persons in a state hospital, or receiving services from a Community Mental Health agency, contact the recipient rights representative. The Recipient Rights number at the Department of Community Health is 800/854-9090.
- Contact Michigan Protection and Advocacy Service (MPAS). MPAS's advocates and attorneys provide information, referral, legal advice, and direct legal representation to persons who are in psychiatric hospitals or receiving other public services. Call toll-free 800/288-5923.
- If the problem seems to be a violation of professional ethics or law, contact the ethics committee of the relevant professional organization. Some professional organizations in Michigan are:

Michigan State Medical Society
120 W. Saginaw
East Lansing, MI 48823 517/337-1351

Michigan Psychiatric Society
15920 West Twelve Mile Road, Suite 203
Southfield, MI 48076 888/810-6226

Michigan Nurses Association
2310 Jolly Oak
Okemos, MI 48864 517/349-5640

National Assn. of Social Workers, Michigan Chapter
230 North Washington Square, Suite 212
Lansing, MI 48933 517/487-1548

Michigan Psychological Association
18296 Middlebelt
Livonia, MI 48150 800/270-9070

III. MENTAL ILLNESS AND THE FAMILY

Coping with a relative who has a mental illness

Reaction of family members

When mental illness strikes, family members are overwhelmed by feelings of bewilderment and guilt. Most deny the seriousness of the situation, at least at first. Exhaustion from being on call 24 hours a day may be coupled with frustration and anger when professionals are unable to accomplish what the family sees as basic: prompt diagnosis and treatment, and assistance to help their relative regain a productive life.

It is not "unloving" to feel resentment in response to the behavior of the relative with mental illness. Realizing the person is ill does not always overcome the hurt, dismay, and anger felt by those trying to help. He/she may rebuff attempts to reach them, and may be fearful or accusatory toward those trying to help. Understandably, families, friends, and co-workers have problems with these symptoms, yet a hostile reaction will almost certainly intensify or lengthen the episode.

It is natural and necessary to grieve for the person who used to be. But strength and determination are needed to meet the coming challenges. Caring, supportive family members can play a vital role in helping their relative to regain the confidence and skills needed for rehabilitation.

Keep in mind:

- Avoid placing blame and guilt. The family did not cause the illness; nor did the person experiencing the illness. Self-blame and blame leveled by others, including mental health professionals, are destructive. Focus instead on the future and on what can be done to develop supportive living arrangements that will enhance the possibility of rehabilitation for your family member.
- Seek the support, understanding and relief you need. Keep yourself healthy and able to cope because you are needed to provide the support your relative needs. Continue your own outside interests. Schedule time for yourself.
- Remember other family members (siblings, grandparents) are affected, too, and they probably are experiencing depression, denial and guilt just as you may be. Keep communication open by talking with them about this.
- Both you and your relative should learn all you can about the illness. Find out about benefits and support systems when things are going well; don't wait for a crisis.

Problem behavior: Here are some suggestions:

- Plan ahead for situations when acute symptoms may recur. Discuss this with the primary therapist or treatment team. Discover if possible which events precipitate these symptoms and agree on a course of action.
- Learn to recognize signs of relapse, such as withdrawal or changes in sleeping and eating habits. The individual may be able to identify early signals of relapse (and should be encouraged to do so). He/she may also be able to tell you what method has worked in the past to relieve stress and gain control of symptoms. A visit to a psychiatrist or other therapist may help prevent a full-blown relapse, particularly when the person needs an adjustment of medications.
- Anticipate troublesome situations. If Aunt Tessie can't handle the relationship, do not invite her when your ill family member is present.
- Do not agree with stopping medications because the condition is "cured," or because the medication "makes me feel sick." Refer these decisions to the doctor who prescribed the medication. Be sure he or she understands your relative's discomfort. A change in medication or doctors may be in order.
- Set reasonable rules and limits and stick to them. It may help to ask the patient's doctor, or a counselor he/she has suggested, to help you do this.
- Do not suggest that the mentally ill person "pull himself together." If he/she could, he/she would. Not being able to do this is part of the illness. Remember, the suffering and distress of the person with mental illness is even greater than your own.
- Do not expect and insist that all disturbing habits be corrected at once. Focus on what is accomplished, not on what is going wrong.
- At times people with mental illness suffer from memory loss or inability to concentrate. Do not insist that the person with mental illness try harder to concentrate; just repeat the information in a nonjudgmental way.
- Do not go along with delusional thinking. The person with mental illness needs to be able to depend on a person who is objective and aware of what is really happening. On the other hand, do not argue with this type of thinking or try to point out faulty logic.
- Your family member may hallucinate; that is, see, feel, hear or otherwise perceive things not perceived by others. Be honest. Accept his or her perceptions as his/her own. If asked, point out simply that you are not experiencing the hallucination. A discussion of how to respond to hallucinations and to other symptoms is an important part of family support and education sessions offered by local hospitals, Community Mental Health, or your NAMI affiliate.

Support and advocacy groups for family members

Your local NAMI group provides support groups for families and friends of persons with mental illness, and often has support groups for siblings and spouses. It is important to share information about mental illness and to understand that serious, long-term mental illness is not caused by the family, or by the person with the illness. Many doctors do not explain the characteristics of the various mental illnesses and the family is left to do its own research. A doctor may carefully explain a blockage in an artery; but may not explain biochemical malfunctions of the brain. "We thought it was our fault," is said too many times. Family members, because of their lack of information, may not be able to provide the support needed.

Unless they have lived with a family member who is mentally ill, it is difficult for most people to understand the everyday trials and concerns of the rest of the family. It is comforting to know that other people deal with almost exactly the same issues and understand. Sometimes they have suggestions and answers; at other times they can only say "Yes, I know." And they do.

In the support group, information is shared about housing, sleeping and eating problems, available social services, medications, their family member's lack of friends and loneliness, your own grief and loss, and fear of taking vacations.

Many people drop in at support group meetings for a few months, get some answers and support for the hard times, and then move on. Often people make lifelong friends. Many people say, "I want to help. I don't want other people to go through what I went through." Some work at making real changes by becoming advocates for better services and care.

If there is not a NAMI support group near you, Community Mental Health Services Programs and private hospitals may offer information and support groups for family members.

IV. INDIVIDUALS WITH MENTAL ILLNESS IN THE COMMUNITY

Community Mental Health Services

There are 46 Community Mental Health Services Programs in Michigan which offer services based on ability to pay. They often give priority for services (especially residential and outreach services) to persons being discharged from the hospital, but they also have responsibility for mentally ill people who have not been hospitalized. They may be able to provide information on other community resources such as peer support groups, drop-in centers, or services for special populations.

Housing

All persons with mental illness have a right to safe, affordable, decent housing. All individuals should have some choice in where and with whom they will live. There is no issue that comes up more often among families of persons with mental illness than housing. Housing options that Community Mental Health may be able to assist in gaining access to include:

- **Community Mental Health group homes or Community Living Facilities.** Operators of these homes have a contract with the Community Mental Health Services Program. They offer group activities and rehabilitation services. They are generally considered transitional, and are often reserved for those being discharged from state hospitals, or from community hospitals under contract with CMHSP.
- **Fairweather Lodges.** These are small group homes designed for a group of individuals who learn to live together, run a home cooperatively, and operate a business for profit with outside assistance as needed. Residents share chores such as cooking and maintenance of the home, and may also jointly operate a small business such as a shop or cleaning service.
- **Adult Foster Care homes (general AFC homes).** These homes are licensed by the Family Independence Agency to provide 24 hour care and supervision of residents, but generally offer little in the way of planned activities or rehabilitation services. Cost is covered by SSI or SSDI payments.

- **Independent living with Community Mental Health outreach services.** Residents may live separately in rooms or apartments, or may share an apartment with others. Intermittent supervision and outreach services are provided by Community Mental Health staff or through an agency under contract to the Community Mental Health Services Program. Rental subsidies may be available through the federal Section 8 rental subsidy program. Contact your local housing authority for information.
- Independent living; alone or with family. This arrangement is generally satisfactory only for persons who are fairly self-sufficient. If there is a Center for Independent Living in your community, they may be helpful with housing arrangements or in securing the assistance needed for independent living.
- Homes for the aged (62 or over), licensed by the Family Independence Agency.
- Nursing homes may admit persons who have mental illness if there are other medical problems as well, or if the diagnosis is dementia.

Rehabilitation

Psychosocial rehabilitation programs should include the following: recreational opportunities, social skills training, employment-related training and assistance, and assistance toward independent living. Limited rehabilitation services are available through Community Mental Health Services Programs and some private hospitals. Assistance with education, training and employment is also available through Michigan Rehabilitation Services.

The Americans with Disabilities Act (ADA), passed by Congress in 1990, is an important federal law which prohibits discrimination against any person with a disability. It also covers individuals who have a history of a disability, or who are regarded by others as impaired, even if they are not. This would include, for example, people who have had psychiatric treatment in the past but are now fully recovered.

The ADA covers employment, public (governmental) services, and public accommodations. Employers may not discriminate against an individual with a disability, including mental illness, if the person is otherwise qualified, by skills and background, for the job. They must also provide "reasonable accommodations" that will allow an otherwise qualified person to perform the essential duties of the job. For more information on the ADA, write to the US Department of Justice, Civil Rights Division, 950 Pennsylvania Ave. NW, Washington, D.C. 20035, or call 202/307-0663 or 800/514-0301 for technical assistance.

Jails and jail diversion

According to one lawyer, "Our jail and prison system is perhaps the greatest danger facing persons with mental illness today." Early intervention when symptoms escalate may succeed in avoiding incarceration, but this may not always be possible. NAMI members need to press county law enforcement agencies and Community Mental Health Services Programs to make it possible to treat, rather than punish, persons who are mentally ill by diverting them from the courts and jails to community residential and treatment programs.

If you cannot afford a private attorney, Legal Aid or the Public Defender may be able to help. The attorney representing your family member should look into release of the person on bond. In cases where this may not be possible, the attorney should make an appropriate motion to ensure treatment while pending trial. If your family member is in jail, it is important to contact the case manager and the physician or psychiatrist as soon as possible. If there is no case manager, find out if the local Community Mental Health Services Program or some other agency has a contract to provide medical and/or psychiatric services to the jail.

It is also important to find an attorney who has some understanding of neurobiological disorders, the legal defenses available, and their impact on the disabled person who is charged. If the offense is of a minor nature, a skilled attorney may be able to arrange for civil commitment to a mental institution in exchange for delaying the criminal case with ultimate dismissal of the charges. Compliance with recommended treatment may be ordered by the court as a condition of probation, or even as an alternative to trial or a substitute for serving time in jail.

Contact with the criminal justice system may provide the first opportunity to identify mental illness and connect the individual with Community Mental Health services. While it may not be possible to avoid the original arrest/incarceration, it should be the goal of the family, the person with mental illness, and the mental health system to eliminate future arrest.

Support groups for consumers

Self-help groups for persons with mental illness can offer an important source of support. Many psychosocial clubhouses offer support in addition to social, educational, and vocational opportunities. Some sources of information:

Manic-Depressive and Depressive Association 734/284-5563 (MWF 9-4)
Michigan Self-Help Clearinghouse 517/484-7373 or 800/777-5556
Schizophrenics Anonymous (Mental Health Association) 800/482-9534

V. FINANCIAL CONSIDERATIONS

Federal programs: SSI, SSDI, Medicaid, Medicare

Mental illness qualifies as a disability. If someone has a mental illness, he or she should apply for government programs so the family will not be financially drained trying to support the person and cover necessary health care. There are two federal disability income programs; SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance). Some persons qualify for both. A family member or advocate may be able to assist with the application process. To apply for SSI or SSDI, call 1/800/772-1213 weekdays between 7 a.m. and 7 p.m. for an appointment, or just drop in at the local Social Security office if you don't mind waiting. Have the Social Security number with you when you call to make the appointment. Bring along the Social Security number, birth certificate or other proof of age and citizenship, information about the home where he/she lives, work history and other sources of financial support, dates of any military service, and information about doctors, hospitals, and institutions where treatment has been received. If you do not have all of the things listed, apply anyway. It is important to apply promptly, since SSI is retroactive only to the date of application, and you may lose SSDI payments as well if you delay in applying.

Supplemental Security Income (SSI)

- To be eligible for SSI based on disability, a person must have a physical or mental impairment which prevents an adult from doing any substantial gainful work, or prevents the child from performing normal activities of daily living, and has lasted or is expected to last at a year or to result in death.
- have little or no income or resources, or in the case of a child under 18 living

with his family, his or her family has little or no income or resources.
- in the case of a child under 18 living with his family, his or her family must have little or no income or resources.

SSI payments may be reduced if the person lives at your home (or elsewhere) without paying his or her share of rent, food, and utilities. If the individual is living with family, make sure everyone understands that he or she is paying for rent, food, and utilities. The person can "owe" the rent money while an application is pending for SSI.

Social Security Disability Insurance (SSDI)
To be eligible for SSDI a person must

- have worked and paid Social Security taxes (FICA) long enough to be covered under Social Security, or be an unmarried son or daughter (with rare exceptions) who became disabled before age 22, who has a parent eligible for retirement/disability/death benefits. The disabled child does not have to be dependent on or financially supported by the parent.
- have a physical or mental impairment that prevents the person from doing any substantial gainful work and has lasted or is expected to last for at least one year.

Having a diagnosis such as "Schizophrenia" does not automatically qualify someone for SSI or SSDI benefits. The question is, how severe is the illness? Written statements by family members describing social problems, difficulty handling money, inappropriate behavior, etc., may be helpful. If benefits are denied, the ruling may be appealed by requesting: (1) reconsideration, (2) a hearing before an administrative law judge, (3) a review of the decision by the Appeals Council, or (4) civil action in federal district court. You have 60 days to appeal between each of these steps. Having an attorney or advocate to guide you through the process can make a big difference.

If the individual with mental illness is unable to manage his/her funds, Social Security may appoint a relative, friend, or other person to serve as "representative payee." This person will receive checks on behalf of the disabled person, and pay for necessary care for the disabled person. It is often helpful to have an outside person deal with financial matters so that family members do not have to haggle about money.

After applying to Social Security for SSI or SSDI, apply for food stamps and

Medicaid at the Family Independence Agency (FIA). Medicare may be available to persons on SSDI, but this happens automatically if they qualify, so there is no separate application to fill out.

Conservatorship

If the person needs assistance in handling money but is not willing to let someone else handle their finances, or if substantial income or property is involved, a family member may have to seek conservatorship through the Probate Court in order to protect the person's finances.

Wills and estate planning

If your relative with mental illness qualifies for SSI benefits, it is very important for the family to plan ahead so that SSI payments and Medicaid will not be lost through inadequate estate planning. By inheriting property or money, your relative may be disqualified for these entitlements, which cover the cost of residential services and medical care. Some families have drawn up a will which simply disqualifies the relative who is mentally ill. A lawyer can also assist in setting up a special needs trust on behalf of the mentally ill person. The trust fund must be restricted so that it cannot be used for basic living costs. If you do not feel you are wealthy enough to leave money for your disabled family member, consider life insurance made payable to the special needs trust.

VI. WORKING WITH THE SYSTEM: How to Get the Help you Need

Families need to know how to be effective in getting help for a family member who is seriously mentally ill.

Here are some suggestions:

- Keep a record of everything. List names, addresses, phone numbers, dates of crisis events, admission and discharge dates for hospitalization. Make notes of conversations and conferences. Make copies of everything you mail. Keep all notices and letters.
- Be polite and keep conversations to the point. Do not allow yourself to be intimidated, and do not try to intimidate the professionals and caregivers.
- Write letters of appreciation when warranted; write letters of criticism when necessary.

Send these to the hospital or agency director, with copies to anyone else who may be involved. Also send copies to your legislator or other state official if necessary.

- Do not be afraid or ashamed to acknowledge that you are the relative of a person who is mentally ill. This is the first step in removing stigma.
- Make sure the person with mental illness is on the same page with you. Do not act at cross purposes unless absolutely necessary to obtain guardianship or involuntary treatment. Help your loved one express his or her needs to the Community Mental Health provider. If those needs are refused, you can go to the Office of Recipient Rights, or to the Administrative Tribunal for Medicaid recipients.
- When all else fails, write to the Administrative Tribunal, Michigan Department of Community Health, P.O. Box 30196, Lansing MI 48909. Include the person's Social Security number and the name of the agency that is failing to help the person. If you want an attorney to help you with this, find one who does "elderlaw," which means the attorney helps people who are elderly or disabled.

Finally, be assertive! You are paying, either directly or through taxes. You are entitled to information, respect and courtesy. You are not asking for favors; you are simply helping to get the job done.

APPENDIX A: Recommended Books

Amador, Xavier, **I Am Not Sick, I Don't Need Help.** Vida Press, 2000.
Barkley, Russell A., **Taking Charge of ADHD: The Complete Authoritative Guide for Parents.** Guilford Press, 1995.
Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM IV). American Psychiatric Association, 1994.
Evans, Katie & J. Michael Sullivan, **Dual Diagnosis: Counseling the Mentally Ill Substance Abuser, 2nd Edition.** Guilford PRess, 2001.
Goldman, Howard H. MD, Ed. **Review of General Psychiatry, 4th Edition.** Appleton & Lange, 1995.
Gorman, Jack, **The Essential Guide to Psychiatric Drugs.** St. Martin's Press, 1997.
Hatfield, Agnes B & Harriet P Lefley, Surviving Mental Illness: **Stress, Coping and Adaptation.** Guilford Press, 1993.
Jamison, Kay Redfield, **An Unquiet Mind: A Memoir of Moods and Madness.** Knopf, 1995.
Keefe, RS & Harvey, PD, **Understanding Schizophrenia: A Guide to the New Research on Causes and Treatment.** Free Press, 1994.
Klein, Donald & Wender, Paul, **Understanding Depression: A Complete Guide to Its Diagnosis, Course and Treatment.** Oxford University Press, 1993.
Lefley, Harriet, **Family Caregiving in Mental Illness.** Sage Publications, 1996.
Manning, Martha, Undercurrents: **A Therapist's Reckoning with her own Depression.** Harper-Collins, 1995.
Marsh, DT & Dickens, RM, **How to Cope with Mental Illness in Your Family: A Self–Care Guide for Siblings, Offspring, and Parents.** Putnam, 1997.
Ross, Jerilyn, **Triumph Over Fear. [anxiety disorders]** Bantam Books, 1994.
Russell, L. Mark, Planning for the Future: **Providing a Meaningful Life for a Child with a Disability After Your Death, 3rd Ed.** American Publishing, 1995.
Sebastian, Richard, **Compulsive Behavior.** Chelsea House, 1993.
Torrey, E. Fuller, **Surviving Schizophrenia, 4th Ed.** Harper & Row, 2001.
Wasow, Mona, **The Skipping Stone: Ripple Effects of Mental illness on the Family.** Science & Behavior Books, 1995.
Woolis, Rebecca, **When Someone You Love Has a Mental Illness: A Handbook for Family, Friends, and Caregivers**. P. Tarcher, 1992.

APPENDIX B: Acronyms and Glossary of Terms

Affective disorder Mood disorder; a psychiatric disorder characterized by extreme or prolonged disturbances of mood such as sadness, apathy, or elation.

Agoraphobia Fear of being in public places; often accompanies panic disorder.

Anxiety disorders Several disorders including phobias, obsessive compulsive disorder, and panic attacks.

Bipolar disorder A major mood disorder characterized by manic and major depressive episodes, with periods of recovery generally separating the mood swings. Psychosis may be present during manic episodes. Also called manic-depression.

CMH Community Mental Health

Compulsion An insistent, intrusive, and unwanted action that is repeated over and over.

Delusions Fixed, irrational ideas not shared by others and not responding to reasoned argument.

ECT Electroconvulsive therapy

Hallucinations Perceptions (sound, sight, etc.) that occur without any external stimulus.

Insight Ability of an individual to understand himself or herself.

Mania A mood disorder characterized by expansiveness, elation, talkativeness, hyperactivity, and excitability. See bipolar disorder.

Monoamine oxidase inhibitor (MAOI) A group of antidepressants that acts by prolonging the effect of neurotransmitters. Generally used to treat persons who do not respond to tricyclic antidepressants. They may cause a serious reaction if taken with certain other medications and foods.

Obsession Irrational thought, image, or idea that is irresistible and recurrent, if unwanted.

Obsessive compulsive disorder (OCD) A major psychiatric disorder characterized by recurrent and persistent thoughts, images, or ideas that are intrusive and senseless (obsessions) and by repetitive, purposeful actions perceived as unnecessary (compulsions).

Panic disorder A psychiatric disorder characterized by sudden, inexplicable attacks of intense fear and body symptoms such as increased heart rate, profuse sweating, and difficulty breathing.

Paranoia Suspiciousness not warranted by circumstances.

Psychosis A mental state characterized by impaired perception of reality, delusions, hallucinations, and distorted thinking. It can be associated with many psychiatric disorders.

Schizophrenia A disease of the brain, the symptoms of which include thought disorders, delusions, hallucinations, apathy, and social withdrawal.

SSDI Social Security Disability Insurance. For persons who are retired or disabled. Dependents may be eligible if diagnosed with a **disability before the age of 22.**

SSI Supplemental Security Income. For indigent, disabled persons. SSDI and SSI are administered through the Social Security office.

SSRI Selective serotonin reuptake inhibitors. A group of antidepressant medications which prolong the effect of the neurotransmitter seritonin.

Tardive dyskinesia A side effect of some antipsychotic drugs, involving abnormal involuntary movements of the tongue, mouth, face, limbs, and occasionally the entire body.

Thought disorder Abnormalities including inability to concentrate or think in a logical sequence; rapid jumping between apparently unrelated thoughts.

APPENDIX C: PETITION/APPLICATION FOR HOSPITALIZATION

STATE OF MICHIGAN PROBATE COURT COUNTY CIRCUIT COURT – FAMILY DIVISION	PETITION / APPLICATION FOR HOSPITALIZATION	FILE NO.

In the matter of _____ Social Security no. _____

Court ORI	Date of birth	Race	Sex

1. I, _____ , an adult _____ petition/apply because I believe the individual above needs treatment.

2. The individual was born on, _____ , lives in _____

County at _____

and can presently be found at _____

3. I believe the individual has mental illness and

☐ a. as a result of this mental illness, the individual can be reasonably expected within the near future to intentionally or unintentionally seriously physically injure self or others, and has engaged in an act or acts or made significant threats that are substantially supportive of this expectation.

☐ b. the individual is unable to attend to those basic physical needs that must be attended to in order to avoid serious harm in the the near future, and has demonstrated that inability by failing to attend to those basic physical needs.

☐ c. the individual's judgement is so impaired s/he is unable to understand the needs for treatment. Continued behavior as the result of this mental illness can be reasonably expected, on the basis of competent clinical opinion, to result in significant physical harm to self or others. (if this is the only item checked, you must file this petition with the court before the person can be hospitalized.)

4. The conclusions stated above are based on

a. my personal observation of the person doing the following acts and saying the following things:

_____

_____

_____

b. conduct and statements that others have seen or heard and have told me about:

_____

by: _____

by: _____

5. The persons interested in these proceedings are

NAME	RELATIONSHIP	ADDRESS	TELEPHONE
	Spouse		
	Gaurdian		

6. The individual ☐ is ☐ is not a veteran

7. I request the court to determine the individual to be a person requiring treatment and that s/he be hospitalized until the hearing.

I declare that this petition/application has been examined by me and that its contents are true to the best of my information, knowledge, and belief.

_____
Date

Name of person assisting in preparing petition — Signature of petitioner

Title and name of agency — Address

Address — City, State, Zip

City, State, Zip — Telephone no. — Home telephone no. — Work telephone no.

Attached is a
☐ clinical certificate by physician or licensed psychologst taken within the last 72 hours
☐ clinical certificate by psychiatrist taken within the last 72 hours.
☐ petition/affidavit for examination (PCM 209) because examination could not be secured.

This Application for Hospitalization was filed with the hospital on _____ at am pm

FOR HOSPITAL USE ONLY

_____
Signature of hospital represantative

The grassroots of AMI

Michigan Department of Community Health

Jennifer M. Granholm, Governor
Janet Olszewski, Director

MDCH is an equal opportunity employer, services and programs provider.